

We Need To Talk

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ABSTRACT

The author looks at end-of-life decisionmaking and communication by summarizing a case well known in the literature and discussing her own experiences in the last days of her father's life. She also presents suggestions for how physicians can improve end-of-life communication to benefit patients, families, and themselves.

KATY'S STORY

In November 2010, Katy Butler, author of the *New York Times* article "What Broke My Father's Heart" (<http://www.nytimes.com/2010/06/20/magazine/20pacemaker-t.html>), was the keynote speaker at Ochsner's inaugural Bioethics Grand Rounds. Katy spoke poignantly and candidly about the death of her father, Jeff Butler, a professor emeritus of history at Wesleyan University.

Professor Butler and his wife of 60 years, Valerie, were a vibrant, active couple. At age 79, Professor Butler suffered a severe stroke that left him almost completely aphasic, unable to complete a sentence, with Valerie as his primary caregiver. Approximately 1 year after his stroke, Jeff Butler told his daughter Katy that Valerie would have been better off if the stroke had killed him because "she'd have wept the weep of a widow. And then she would have been all right." After the stroke, Valerie reportedly never saw her husband smile.

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In January 2003, Professor Butler saw a general surgeon for an inguinal hernia. Because Professor Butler had bradycardia, a cardiologist refused to clear him for surgery unless Professor Butler had a pacemaker implanted. The Butlers were not advised that an external pacemaker could have been used during the surgery and then removed following the surgery. Valerie had to make the decision, and relying on the advice of the cardiologist and general surgeon, she signed the consent for her husband to have a pacemaker implanted. Importantly, prior to his stroke, Professor Butler had been offered a pacemaker for the same bradycardia and, after consulting with his trusted primary care physician, chose not to have the pacemaker implanted. That same primary care physician was not consulted after the stroke and was not involved in discussions regarding the pacemaker. The battery for the internal pacemaker was expected to last 10 years.

A steady deterioration of Jeff Butler's health followed. By 2005, he was nearly deaf, and wet macular degeneration rendered him severely visually impaired. He was incontinent, and a fall resulted in a brain hemorrhage that left him with some disturbing compulsive behaviors. Valerie continued to be his primary caregiver, and at age 80, she was working 80-hour weeks.

In fall 2007, 4½ years after the pacemaker was implanted, Valerie asked Katy to assist her in having the pacemaker deactivated, stating that she wanted to do for her husband what she would want him to do for her. Never questioning her mother's motives, Katy agreed to help. They contacted the cardiologist who had originally implanted the pacemaker and asked him to deactivate it, a procedure that could be done without surgery.* The cardiologist refused to deactivate the pacemaker for fear that Professor Butler would "die immediately." The physician later told Katy that "it would have been like putting a pillow over

*The Heart Rhythm Society published a position paper about this issue (<http://www.hrsonline.org/PatientInfo/Treatments/eol-and-devices.cfm>), stating that deactivating a pacemaker is ethical and not euthanasia.

your father's head."[†] When Katy and Valerie asked the physician to contact other doctors who might be willing to deactivate the pacemaker, he said that he could find no physician willing to do so. Thus, Professor Butler's pacemaker remained in place and continued functioning.

Approximately 6 months later, Professor Butler contracted pneumonia, at which time Valerie refused all but palliative care. More than 5 years after the pacemaker was implanted, Professor Butler died, with the device still working perfectly.

One year after her husband's death, Valerie was faced with her own difficult medical decision. She was diagnosed with aortic and mitral valve insufficiency, and her doctors recommended valve replacements. Valerie visited her cardiac surgeon wearing a do-not-resuscitate (DNR) anklet. The surgeon refused to operate on her with the anklet in place, stating that it "would not be fair to his team." Because the risk of stroke is always present with cardiopulmonary bypass, Valerie asked the surgeon if he would agree to let her die if she had a stroke on the operating table. He wanted to know how she would feel about a "minor stroke," which he described as "a little weakness on one side." Valerie made the decision to forego surgery and died with great dignity a few months later—fully competent and fully continent. Katy believes that her mother's life was cut short by almost exactly the number of years her father's life was artificially extended.

Katy's definition of end of life goes beyond the 5 days before a ventilator is disconnected in the ICU. She says end of life is "when medicine cannot restore someone to the level of previous functioning—when they are losing chunks of themselves and chunks of their lives." Katy calls on us to broaden our focus when we talk about end of life to include the members of the patient's family whose lives will be inexorably changed and diminished by caring for someone with very little quality of life. Katy is adamant that physicians should be clear about the options available to patients and should not protect patients when telling them what life will probably be like with each option. Patients must understand what they are agreeing to undergo.

[†]See Dr Abi-Samra's article on this very topic on p. 342 of this issue of *The Ochsner Journal*. Also, Louisiana law makes clear that there is no distinction between withholding and withdrawal of life support. A physician who cannot implement the patient's wishes must make reasonable efforts to transfer the patient to a physician who can comply with the patient's or family's request (La. R.S. 40:1299.58.7).

Katy adds that patients desperately need their doctors to be witnesses to their suffering—to sit with them in their suffering and not to run from it. Patients need frank conversations and explicit information about options. Patients need conversation and information much more than the high tech knowledge physicians often want to provide.

LISA'S STORY

Although I had been around hospitals for approximately 20 years, my father's death was my first personal experience with end-of-life issues. When my dad was 75 years old, he suffered from moderate dementia and significant mobility issues as a result of diabetic neuropathy. He hated to go to the doctor and often left a physician's office after 10 minutes in the waiting room.

In January 1994, my father was found incoherent after a fall. A chest x-ray revealed a very large tumor in his left lower lobe, presumably metastasis from a malignant tongue lesion that had been removed 18 months before. The tumor produced calcium and made my father incoherent and delusional. The oncologist suggested 6 months of daily radiation, followed by chemotherapy. I explained that I did not believe my father could tolerate that regimen and, unless the doctor thought there was a good chance at meaningful recovery, I did not think it was a viable option. The oncologist evaded my questions. A friend of mine who was also an oncologist informed me that what my father had was incurable, and while radiation and chemo might shrink the lesion, my father's life expectancy would still only be approximately 12 months.

I suggested to the lead staff oncologist that he enter a DNR order. The physician responded that he would not do that without speaking with my father. We scheduled a meeting for the following morning at 8:00 am. I arrived at about 7:55 am, just as the physician was leaving my father's room. The physician said to me, "I spoke with your father, and he wants to live." In that moment, I felt that the physician was accusing me of wishing my father dead. I took a hard look at my motives and was comfortable in the knowledge that I was trying to avoid having my father suffer with no more than a remote chance of survival. I thought the downside of the recommended radiation/chemo regimen far outweighed the possible benefits, and I believed my father was not competent to make his own decision. After consulting with other members of my family, I again asked the physician to enter a DNR order, and he reluctantly agreed.

The next day, as I approached my father's hospital room, I could hear him screaming in pain. As I walked through the door, I saw a resident performing a

thoracentesis. When I asked what he was doing, the resident responded, “We need fluid to send for analysis.” Apparently, the physicians wanted to be 100% sure the tumor was malignant. I reminded the resident that my father had a DNR order and that this procedure did not seem consistent with that order. Further investigation revealed that the staff oncologist had not, in fact, entered the DNR order. When the DNR order was ultimately written, the discussion turned to whether it was appropriate to give my father sufficient morphine to control his pain and feelings of suffocation, because that amount of morphine would suppress respiration. After 2 long days of discussion, the doctors ordered Haldol to be administered, and my father was comfortable during the last day of his life.

WHO CONTROLS THE END OF LIFE?

Katy Butler believes that her parents lost “control of their lives to a set of perverse financial incentives—for cardiologists, hospitals and especially the manufacturers of advanced medical devices—skewed to promote maximum treatment. At a point hard to precisely define, they stopped being beneficiaries of the war on sudden death and became its victims.” She also believes that Medicare’s refusal to provide fair compensation for physician-patient conversations, along with its agreement to pay for procedures, discourages meaningful physician-patient conversations.

I recognize that Katy Butler’s point of view is valid. However, my 20 years of experience representing physicians and hospitals and serving on a bioethics committee, as well as my experience as a daughter, lead me to a different conclusion.[‡] I believe physicians continue to provide treatment without having meaningful discussions with patients and families for other reasons: 1) Physicians often do not know how to have difficult conversations, and 2) physicians often do not prioritize conversations over other tasks. It is often easier, and certainly more comfortable, for a physician to continue orders for futile care than to explain to a family why care should not be continued and specifically why he or she is not willing to continue futile care. While many physicians are virtuosos of difficult conversations, many more of them are novices at best. This deficiency may not be the fault

of the physicians, most of whom are not specifically taught how to have difficult conversations. The art of having these conversations is primarily learned on the job, and there are not many available mentors.

HAVING CONVERSATIONS WITH DYING PATIENTS AND FAMILY MEMBERS

I believe patients and family members who are facing death want conversation and want the conversation to include certain elements. If a physician truly cares about his or her patients, and the vast majority do, conversation is a skill he or she can learn. Primarily, patients want to know that their physician really “sees” them as the human beings they are. They want to know that their physician understands the value of the cargo they are carrying. Before the wife of a dying patient hears about the panic value of her husband’s PO₂, she wants to hear something like this: “Ms. Smith, I can only imagine how difficult it must be for you to see Mr. Smith declining so rapidly. You and Mr. Smith have been married for 62 years, and you may be losing your best friend. If I were you, I would be terrified. I have only been married 12 years, and the thought of losing my wife is unbearable; I cannot imagine it 50 years from now. I want you to know that I have some idea what Mr. Smith means to you, and you have my assurance that I will do anything I can that will make his disease process better and absolutely everything that will make him comfortable. I want your permission, however, not to do anything that will not help his disease process or will make him uncomfortable. Should his heart stop beating, I want you to be able to sit with him in those last minutes—not be rushed from the room so we can do procedures that will make him very uncomfortable and will not prolong his life.”

Families and patients want physicians to broach the subjects of quality of life and the benefits/risks of a procedure—prior to performing the procedure or instituting therapies that will have a radical impact on their quality of life. Family members who are caring for their loved ones often do not know that there are alternatives to proceeding with more treatment. They do not know that stopping is an option. Caregivers are often very invested in being perceived as loving and caring, and it is counterintuitive to approach a physician with questions about whether it is time to stop treatment. Physicians who are comfortable with difficult conversations can help families make these sometimes excruciating decisions by truthfully and compassionately conveying the information they would want to have when making such an important decision. Patients want honest information delivered with great compassion. Most do not want to be protected from the truth.

[‡]Disclosure of one potential bias to my view: My work has been primarily with a group practice healthcare system where physicians are salaried, so the medical decisions they make do not have any direct impact on their salary or their malpractice costs. Some may see a different picture when medical decisionmaking has a direct impact on the income this month or on fears that such a decision may escalate malpractice costs.

HARMS OF FUTILE CARE

In my experience, when physicians continue futile care simply because the treatment is available but do not consider the consequences to the patient and family, such a decision also takes a huge toll on healthcare providers as well. I recall a 2-year-old child who underwent a liver transplant. The initial transplant failed, and a second liver was transplanted. When the second liver began to fail, the physicians were reluctant to give a lot of pain medication for fear of damaging the liver, and the nursing staff reported that the child was in excruciating pain. When the physician team approached the family about consent for a third transplant, the nursing team protested en masse. Eventually, the child was allowed to die, with his parents and grandparents at his bedside.

When a family will not allow a terminal patient to die, nurses who are required to render care that causes a patient pain suffer a great deal. I recall a young man whose mother believed he was going to improve, even after physicians told her there was no chance of recovery, short of a miracle. He had an open abdominal wound that needed almost daily dressing changes that were very painful to the patient. Nurses had to be rotated to avoid burnout.

HOW PHYSICIANS CAN IMPROVE END-OF-LIFE CARE

I believe physicians can take 6 steps to improve end-of-life care:

1. Examine their own beliefs about death and quality of life. Take a hard look at whether they

fear death and believe life should be sustained at any cost.

2. Examine their fears of being sued. Physicians often express a fear of being sued for discontinuing life support, when, in fact, there is very little risk of a lawsuit when life support is discontinued following a good conversation with family members.[§]
3. Commit to improve skills related to difficult end-of-life conversations, and in teaching institutions commit to teaching residents these skills.
4. Lobby for restructuring reimbursement to ensure that physicians do not lose money for having conversations that would ultimately result in less futile care.
5. Prior to performing a procedure, rigorously examine whether they are performing the procedure simply because it can be done. Through conversation with the patient and family, sincerely explore whether the next step is, in fact, the right thing to do for the patient and the patient's family. Talk with the family about the probability of success of the procedure and how the patient and/or family define a successful outcome.
6. When a patient appears to be near the end of life, commit to examining each order or procedure to determine whether it is helping the patient's disease process or making the patient more comfortable. If it is doing neither of these, think long and hard before entering the order or performing the procedure.

This article meets the Accreditation Council for Graduate Medical Education and American Board of Medical Specialties Maintenance of Certification competencies for Patient Care and Medical Knowledge.

[§]Louisiana state law provides immunity for physicians who withhold or withdraw life support with an advance directive (RS 40:1299.58.8).